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The Ecological Being: Anandgram and the Expanded Leprous Body Rachel Armstrong

ABSTRACT This paper establishes a framework for the reading of an ecological identity by focusing on the author's sabbatical experience working as a medical student with patients at Anandgram – the Village of Joy – in 1991. Anandgram is a leprosy hospital and rehabilitation center situated on the outskirts of Pune, India. It is home to a unique community of outcasts ravaged by the disease. Despite overwhelming odds, these people have overcome the constraints of a singular identity – that of the leper – and reclaimed a productive future for themselves. The ways that Anandgram's residents have forged new kinds of existence have far-reaching implications for the built environment through their impact on identity, technology, ecology, culture, materiality, and the production of spaces. With this in mind, the aim is to present a portrait of the leprosy body not as a machine but as an “ecological being,” a dynamic model of human anatomy that is in continual flux and deeply embedded with the environment.

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Introduction: Leprosy and its Impact

I found myself inhuman ...
People cast me off, I inhuman.

Don't look at me!

– Inhuman.”

(Chris Casaba, “Leprosy”)¹

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My research questions regarding the design of the human body and its relationship with the environment began to formulate themselves when I was a medical student in 1991.² I elected to spend time at Anandgram – the Village of Joy – a leprosy hospital and rehabilitation centre situated on the outskirts of Pune, India, during an optional sabbatical study period before my final clinical medical exams. Despite overwhelming odds against their success, the residents of this community choreographed an inventive synthesis of technology and architecture to lay claim to a new identity for themselves and create the foundations of a productive economic and socially integrated future.

Leprosy is a terrible infection. It is one the oldest diseases known to us. The earliest reference to it appears in an Egyptian papyrus document written c. 1550 BCE. It is caused by the bacterium *Mycobacterium leprae*, which was isolated by Dr Gerhard Armauer Hansen in 1873. Despite its significance, both historic and contemporary, it has still not been cultured in a laboratory setting, and not much is known about how the disease is contracted or spread. It infects soft structures, particularly the sensory nerves and connective tissues, such as cartilage. The condition can be cured if detected during the early stages of infection. Typically, the first sign of the disease is a depigmented patch of skin, which can sometimes be mistaken for the autoimmune condition vitiligo. At this stage, if there are no other ill-effects such as nerve damage, then the condition is completely curable using a vigorous and lengthy regimen of antibiotics.

However, the infection is often left untreated, owing to the stigma that contracting the disease brings. Contaminated nerves and soft tissues are progressively destroyed and lead to sensory loss, leaving the body unable to protect itself from everyday traumas. Depending on the site of infection, gradual impairments may result in major physical changes. For example, facial infections leave corneas unprotected against drying gusts of wind that result in scarring and blindness. When feet are infected, a person will walk without automatically spreading their weight, resulting in chronic “march” (or Charcot) fractures. People may also suffer the indignity of “stigmata” which mark them out as potentially carrying the disfiguring infection – these include loss of nasal cartilages, which give a “lion-like” appearance to the face, and loss of digits (Figures 1 and 2). Sadly, once these physical changes take place, they are permanent and require active or palliative interventions.

Arguably, the social and psychological consequences of contracting the bacillus are more deadly than the chronic physical effects of the untreated infection. The deep-seated fear and misunderstanding of leprosy causes sufferers to be rejected from their communities – even by their nearest and dearest – and results

Figure 1

*Hansens Hands 7.*Credit: Rachel Armstrong,
movie still, 1991.Caption: Stigmata of leprosy
include the "lion shaped"
nose where cartilages have
been destroyed by infection.

in a negative spiral of social exclusion and societal reinforcement that prevents people seeking treatment. A diagnosis of leprosy is much more than a set of physical symptoms; it profoundly affects many aspects of a person's life, including mobility, interpersonal relationships, marriage, employment, leisure activities, and access to social functions.

Reconfiguring the Leprous Body

At Anandgram, I was assisting a hand surgeon, who re-threaded tendons in patients with critical loss of hand function. By sacrificing less important muscle groups and rerouting the tendons to new sites of attachment, it was possible to revitalize movements in major groups of muscles that had been permanently damaged by leprosy. These operations were performed without general anesthetic because the patients could not feel any surgical pain in afflicted areas. Part of my role was to make polite conversation with a fully awake patient; the other to assist the surgeon in performing complex surgery – this in a bare, sterile room. Through this simple approach my colleague could complete

Figure 2

*Hansens Hands 14.*Credit: Rachel Armstrong,
movie still, 1991.Caption: Constant trauma
to hands causes the fingers
to be destroyed.



Figure 3
Hansens Hands 25.
Credit: Rachel Armstrong,
movie still, 1991.
Caption: Corrective surgery
through tendon transfer **is**
observed as a prominent
incision on the left cheek,
which involves splitting of
the masseter muscle.

intricate and sometimes lengthy procedures, without the normal cost
of an anesthetist. It was also possible to assess directly the immediate
success of the surgery by asking patients to move their hands during
the procedure. These visceral, restorative procedures were not confined
to hand function but could also be applied to other important muscle
groups. One operation involved splitting a face muscle tendon and
attaching it to the inner corner of the eye. This allowed people who had
lost the ability to blink to do so voluntarily, by clenching their teeth. With
intensive training, eye drops, chewing gum, and rehabilitation, those
who had undergone the procedure were able consciously to prevent
their corneas from scarring through dryness and, ultimately, to save
themselves from blindness (Figure 3).

Beyond the operating room, the Anandgram community itself
created a supportive environment for rehabilitation. Tendon transfer
patients were actively encouraged to use, and to continue to use, their
rewired bodies. From the moment the patient left the operating theatre,
their relocated, reallocated muscle insertions moved different parts
of their body than they were formerly habituated to, and therefore
immersed them in a novel reality. Patients emerged like children,
calibrating their being-in-the-world. In fact, the whole village was
an experimental environment full of ready-made technologies and a
community that was not alienated by "difference." The village itself had
evolved out of a collaborative effort that began as an unauthorized
settlement on the outskirts of Pune, where outcasts banded together
to restore their self-respect and independence. In 1970, they secured a
grant from Oxfam that enabled them officially to buy an arid eighteen
acres of rocky, undulating land. This was situated near the village
of Alandi, where the thirteenth-century Maharashtrian Hindu saint
Dyaneshwar achieved enlightenment. This holy figure is celebrated for
performing miracles such as baking bread upon his heated back and
making a wall move. Here, the Anandgram residents achieved their own

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miracle by transforming poor-quality land, which could support little more than a few stubborn shrubs, into a farmable terrain.

The journey towards self-sufficiency was inaugurated on October 17, 1970. Houses were built and jobs secured through the ingenious and widespread use of prostheses. Simple technologies and tools enabled the residents to cook, farm, and produce fabrics. They learned how to customize a whole range of operating interfaces to compensate for specific impairments that could not be restored by surgery, such as dropped feet that dragged on the ground.³ Bodies were transiently coupled with, and transformed by, a range of devices that restored a sense of wholeness to residents, now able to earn a living. In this way, the community could transgress the limits of deep-rooted social stigma using a range of highly adapted technical platforms. They could reclaim their dignity and self-respect, which broader society had ruthlessly denied them.

In this environment, it is impossible to identify a hierarchy of actors, or identify simple causes and effects, that enable such a remarkable transformation. Anandgram's premises were organized so that living places and workspaces were entangled. Manufacturing workshops were within easy walking distance of the residences, individual homes were simply laid out with access to basic facilities with kitchen ranges, running water, bedrooms, and a shared large social space, while communal outdoor spaces were pleasantly landscaped. Trees shook with the song of cicadas and provided welcome shade for picnics where we sat on hand-hewn benches. Vibrant floral blooms exploded with impossible vigor from the sandy soils. People appeared to have time for each other and, despite their strange prostheses, they radiated palpable congruence with the natural world.

While the unfamiliar appearance of residents defied classical notions of physical symmetry, a "purity" of form, or even a logical hierarchy of physical order where particular bones are moved by specific muscles, their incongruities spoke of a new kind of anatomical configuration. The combined synthesis between the destructive actions of the leprosy bacillus, rethreaded muscle tendons, temporary prostheses, highly customized tools, and the unique character of these bespoke entanglements, asserted that people were neither well-circumscribed objects nor machines. Rather than appearing machine-like with their prostheses, the Anandgram residents themselves seemed to humanize the technologies that surrounded and constituted them. Despite being in an altered body, villagers were empowered by the way their structures built on existing physiological, anatomical, cognitive, social, and environmental connections. In turn, each person's unique anatomy became a site for the entanglement of new networks and relationships.

Beyond Individuals

Physiological and anatomical

Following their reconstructive surgery, Anandgram residents were not just anatomically restored “human beings.” Owing to their diverse range of appearances, various prostheses, behaviors, and personalities, they could also more inclusively be described as “ecological beings.” Augmented by their expanded connectivity through simple technologies, they actively forged new networks of social, cultural, and even economic interactions.

Dropped feet were protected by attaching leather thongs to toes and shins, strung like a bow around the front of the leg. Automobile-tire-soled shoes distributed weight sequentially over the entire surface area of feet and prevented traumatic fractures. Some residents brachi-ated, crab-like, on wooden appendages to spare excessive strain on newly strengthening tendon attachments. Their ease of locomotion was remarkable for its ordinariness. The various technologies were even adopted as fashions, being worn with pride. Grubby bandages were wound decoratively around numb areas of skin. Residents that had lost the upper soft palate fashioned new noses by hand from hot wax. These prostheses were inserted into the cavity left in the roof of the mouth to provide support for the flabby nasal tissues whose cartilages had been destroyed by the infection. Invariably, this had also claimed the upper teeth, and the insertions countered the “lion-like” features caused by the disease (Figures 4 and 5). While medical professionals advised sunglasses as protective devices to prevent corneal drying, residents also regarded them as accessories and status symbols.

These simple, low-tech technologies were successful not just because they served to replace a body object that had been lost, or even to augment the existing body machine by adding a new component, but by increasing each person's self-esteem and extending their sphere of influence within their family, community, and their habitat. As their capacity to rearticulate their abilities within their social spaces expanded through a newly empowered anatomical configuration, residents gained increased independence and new capacities to build enriched forms of social interaction with the wider community.

Cognitive and social

In Anandgram, the success of tendon transfers was not primarily to do with how a person's body had anatomically been reconfigured, or with the efficiency of the relocated structures in providing rehabilitative support, but with how each individual resident was re-enabled and inspired to explore their newly expanded environment. In essence, this community subverted the traditional western notions of ideal morphologies, such as a preference for symmetry or conformity to a particular body plan. They also subverted the assumption at the heart of my medical training – that the human body was fundamentally mechanical in its ordering.

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Figure 4

Hansens Hands 29.

Credit: Rachel Armstrong,

movie still, 1991. Caption:

Nasal prosthesis to correct

a fallen nasal cartilage also

involves replacing the upper

teeth, which are lost when

the soft palate collapses.



Rather than valuing people, things or tools, and places, each constituted separately, Anandgram asks us to think in terms of ever-shifting relationships between the animate, the inanimate and the environment. Self, family, and community are also fluid concepts. The political system in the village is not centered on social hierarchies based on a caste structure, prevalent in Pune, or even on anatomical typologies derived from the differential effects of the stigmatizing illness, but around a notion of kinship. This sense of inclusion creates an extended notion of community within the village as people are bound together in shared survival and an ambition to thrive. Indeed, the ecological politics of Anandgram have the capacity to change social status within the village in ways that do not exist outside this site. People within Anandgram can marry, raise children, form extended families and enjoy lives without social prejudice. Potential inequalities can be continually negotiated through an alternative value system to reaffirm belonging both within and beyond the village – Anandgram residents trade their goods in Pune.

Figure 5

Hansens Hands 30.

Credit: Rachel Armstrong,

movie still, 1991. Caption:

Demonstrating how to

insert the nasal prosthesis

through the roof of the

mouth.



Such cultural contracts transcend traditional notions of status and identity whereby previously those with leprosy were viewed as “untouchable.” Now, they are in economic partnerships with the broader community. That is not to say that prevalent social order is irrelevant. Beyond the village those with the stigmata of leprosy are still generally excluded. But within the Anandgram community the alternative ethics shape freedoms previously unthinkable for those whose lives seemed, frankly, destroyed.

The traditional boundaries of what it means to be “human” in Anandgram in this context have been extended, leaking well beyond the stringent definitions posed by classical western ideals of form and function. But in this, Anandgram shares many issues with modern Western communities, which depend just as much on supportive environments and technical systems. While those who have been afflicted with the sequelae of leprosy infection may be socially reconstituted by association with a range of prosthetic technologies, our first world societies also place technological systems as integral to our culture. Indeed, we naturalize technology to the point where not only are its systems no longer considered strange, but may even be considered indispensable to our identity – think of the way that our contact lenses and smart phones have become extensions of ourselves.

The rehabilitation processes I saw respected traditional cultural perspectives while embracing new values, and granted status to different physical configurations that reflected the constantly evolving needs of the community. Of course, Anandgram had limits of technical and social plasticity. These were reached when surgical procedures were unsuccessful, prostheses broke down, tools were suboptimally modified, family traumas occurred, existential crises began, and broken hearts cried – just like any other collective of “humans.” Yet the stories that shaped this vibrant place emphasized the inseparable interconnections between people, technology, anatomy, and environment.

Environmental

The founding politics, identity, value systems, culture, and ethics of such “ecological” communities are far from formalized. Yet in recent years, a range of “new materialist” perspectives that explicitly seek to raise the status of inanimate matter from object to “actor” has emerged. Notions of participatory inclusion can be found in texts such as Bruno Latour’s actor-network theory (ANT), which treats objects as part of social networks; Karen Barad’s agential realism, whereby “objects” emerge through discursive relationships between networks and matter; Jane Bennett’s vital materialism, in which materials possess their own trajectories, potentialities, and tendencies independently from human agendas; Donna Haraway’s companion species and cyborg manifestos, which propose the foundations for non-human politics; and Graham Harman’s object-oriented ontology, which rejects the privilege of humans

over nonhumans.⁴ When these new materialist ideas are contextualized by Timothy Morton's concept of "dark ecology," the idea of the natural realm is deconstructed as more than a bucolic utopia. Instead, we are asked to consider the interconnectedness of the natural realm as a fundamental condition that is "dark," invoking hesitation, uncertainty, irony, and thoughtfulness.⁵

Ecological beings

In considering the protean nature of the being revealed by the alternative forms of material, social and ecological systems in Anandgram, our attention is drawn to the flexibility of humanity. This fluid identity can be thought of as "ecological being." It is not fixed in terms of its material or anatomical relationships but can deploy shape-shifting operational systems to be flexibly discursive within collectives about where the values and identifying factors reside. In finding sympathy with other life-forms, new discourses may potentially be established without diminishing ourselves and precipitating social atrocities of a different kind and order from those we are all too familiar with now. While such ambitions may at first seem utopian, they cannot exist without skirmishes such as boundary conflicts, issues of identity and cultural conflicts.

Yet implicit in the possibilities for constructing identity, relationships and kin, the ecological being resists determinism and even formal categorization. It is no more possible to design or anticipate the relationships and networks that comprise an ecological being than it is to predict the evolution of a swim bladder from studying the developmental biology of a lungfish.⁶ So, in thinking about what a body might become we have to consider all the possible trajectories that an organism may take in its route towards a future form of survival. Frankly this is incalculable. While we may be able to post-rationalize how an organism made the transition say, from water to land, we do not have the capability to observe a living system and predict all possible future states, let alone to know how fast or slowly these may occur. But not knowing what an "ecological being" might be in the future does not preclude us from considering the principles of its existence and establishing sympathy with other bodies, beings and creatures.

Indeed, the ecological being is not constrained by its specific anatomy. It is an organism that is sympathetic to and entangled with humanity, but may not be exclusively human. Owing to this lack of purity, the ecological being is protean and embraces many future configurations that are yet to be expressed. It identifies with humanity through an extended realm of material and cultural connections which are produced by the combined interaction between complex interdependent agents and networks that are collectively recognized as its flesh. These are not discrete accumulations of identical tissues, but exist at the transition zones of cellular organization. Such assemblages may also find transient or persistent commonality with biospherical, technological, cultural,

Figure 6
i-cological_larger_inverted_V11.
Credit: Simone Ferracina,
2013.
Caption: Ecological being.
This iconic representation
indicates the semi-
permeability, connectivity,
and protean nature of
a being that succeeds
humans and views itself
as being entangled in
biospherical relationships
that become integral to its
identity.

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material, and social processes as well as other specific agents – for example, intestinal bacteria, trees, implants, or gadgets – which may even be regarded as “part” of a being. Some of these relationships are obligate, so we cannot do without them (like the energy-producing networks of mitochondria), but many (like smartphones) are associative, where we have a choice.

Existing in such a highly dynamic, materially heterogeneous and networked state, the ecological being is porous to invasion. It is constantly patrolled and remade at its limits. It therefore does not have an ideal form, but signifies a paradox of existence. Its community includes chameleons, shape-shifters, transformers, mutants, the offspring of multiple parents, the bacterial biome, tissue cultures and changelings – beings that invite multiple social readings at the level of individual bodies and as a collective. The ecological being brings value to these communities by sharing its network of operations, and entangling the constituent bodies with each other to produce meaning and value, which may be assimilated by human cultures. For example, a child produced by egg donation in a surrogate womb transcends traditional notions of heritable identity. So does someone living with an organ transplant.

Possible notions of re-identification as human can even extend beyond the associations that we make with tissues and cells of our own species. Notable non-human members of the ecological being include the bacterial biome – an interiorized world that consists of a community of human-dwelling bacteria. These are so numerous that on a cell-for-cell basis only one in ten of the cells that make up our

bodies possess human DNA. Yet, because of their tiny size, bacteria only make up a few kilograms of our body mass. While we have overlooked the role of our bacterial biome in the modern age, it nonetheless produces essential fats, digests our food, and provides immunity against pathogens – functions that are destroyed in the presence of excessive antibiotics.⁷ Moreover, transformed human cells could also conceivably be considered as ecological beings. For example, in 1951, cervical cells (HeLa) belonging to Henrietta Lacks were used to produce an “immortal” cell line that could live outside her body and were therefore used for medical and biological research into conditions including cancer, autoimmune deficiency syndrome (AIDS), radiation sickness, and gene mapping. It is estimated that there are now more than twenty tons of HeLa cells in existence, a situation that raises complex moral, political, and ethical questions about their status.⁸

In the face of such overwhelming variety of agents and potential candidates, how is it possible to maintain any kind of coherent sense of identity for ecological beings, which do not surrender a sense of “self” despite their inherent fluidity and relentlessly material nature. The ecological being is coherent, and does not invest in reckless metamorphoses. Rather, it expands the limits of its operations through promiscuous relationships and modes of self-expression. This nascent hypercomplexity is expressed as a diverse portfolio of creativity. Identity, community, and kin are formed through the editing processes that occur between the ecological being’s entanglements with other bodies and fields of experience. The provocative questions that these beings raise will need to be constantly addressed within their many contexts.

Fundamentally, the ecological being is an “ecosystem of being” that is nested within other ecosystems and freely inhabits a world in flux through the fundamental creativity of its production processes, which may – or may not – be naturalized. The ecological being presents an operational framework where anatomical and social relationships are an instrumented ecology that is coaxed into existence through its material entanglements with technology, ecology and culture, in ways that may draw inspiration from the residents of Anandgram. It is only at the point where the essence of our existence has been thoroughly deconstructed and subjected to new kinds of propositions that it becomes possible to apply shared visions, ethics, and values, to freely reconstruct our relationships within new contexts. Through the various possibilities, alternative futures and ways of living may be realized that may help us navigate some of the complex issues presented, for example, in the millennial rise of megacities, where many different kinds of people and agencies coexist with each other.

Alternative modes of existence through a different kind of (re) telling of the story of life on Earth are needed, so that, in an ecological context, the future of one life-form is not prejudiced over another. Yet ecological relationships are not without their challenges. While they respond to changing conditions and can manage the risks associated

with novelty in a plethora of different ways, such as using immune systems to patrol interactions between bodies, their negotiations cannot be absolutes. They must be shaped by continual diplomatic exchanges capable of responding to a host of variable circumstances in which both human and nonhuman are implicated.

If we propose to raise the status of the nonhuman realm, it is also necessary to accept the impossibility of entirely removing ourselves from the establishment of emerging or future communities. Not only would this require us to uncouple from our current, bounded existence, it would also inevitably reduce the status of humanity, with serious ethical consequences. Indeed, practical and ethical concerns are raised when co-designing and engineering ecosystems alongside non-humans. Yet, by attending to the needs of the non-human as well as of ourselves, we initiate the process of strengthening our relationships and building alternative communities in which our common survival is mutually beneficial. In turn, such acts of trust extend our direct realm of influence and increase material creativity across many scales of integration and sites of action. Such possibilities are at the heart of robust and diverse communities. Moreover, ecology is more than a biophysical strategy through which spaces can be differentially occupied. It also produces politics and practices that can buffer against conflict. This is not to say that population-scale extinctions might not occur; rather, it is to say that the complex continual negotiations within multiply-inhabited communities have great capacity to productively and creatively coexist.

Through the constant renegotiation of boundaries, it may be possible to confront differences to establish and maintain hypercomplex, highly agile societies. Within the finite environment of a community, our innate relationship with ecosystems may help us develop alternative relationships with "humans" and also form other kinds of kinship. Through the political, biophysical, ethical, and social framing of the ecological being, ways of thinking about what it means to be "human" could promote the formation and coalescence of diverse cultures. The unbounded possibilities for new syntheses between the myriad agents that comprise a body encourage the kind of potency and variation that offer us a chance of ongoing futures, as we seek purchase within the challenging environments that comprise our millennial megacities.

[T]hey had tools that crept, slithered, flew, but they had made these things. [...] They built things with bacteria. [...] Bacteria which were themselves traceable to the aliens' own intestinal flora, infecting everything.⁹

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Notes

- 1 “Leprosy” by Chris Casaba (2014). Available online: <http://allpoetry.com/poem/10981685-Leprosy-by-Kalesa/>.
- 2 Rachel Armstrong, “An Unexpected Guest,” in *More Women Travel: Adventures and Advice from More than 60 Countries*, a *Rough Guide Special*, ed. Natania Jansz and Miranda Davies (London: Rough Guides, 1995), 310–318.
- 3 “Dropped foot” is a medical term for nerve or muscle damage that causes people to scrape the front of the foot on the ground.
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